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ABSTRACT

The paper discusses the rationale and guidelines for parent involvement in HCEEP (Handicapped Children's Early Education Program) projects. Ways of assessing parents' needs are reviewed, as are four types of services to meet the identified needs: parent education, direct participation, parent counseling, and parent provided programs. Materials and approaches are recommended for each of the four delivery types. The parent education approach is considered in terms of teaching parents to participate in individualized education program planning, and providing information on such topics as normal growth and development and special skills needed to provide care for their child. The description of the direct participation approach focuses on work with fathers, and new approaches such as the Portage Project. Parent counseling emphasizes coping patterns and lists criteria for successful counseling. Parent organizations and parent to parent programs are sources of parent provided programs. A section on evaluation of parent involvement programs touches on ways to measure parent satisfaction; program effectiveness; changes in parent knowledge, skills, and attitudes; and the degree to which services are used. (CL)

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# Parent Involvement

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# PARENT INVOLVEMENT

HCEEP demonstration projects serve an extremely heterogeneous population--children from diverse age groups, with different handicaps and displaying unique needs. Yet all projects, regardless of the characteristics of the children or the educational or socioeconomic background of the parents, stress parent involvement as a basic component of their educational model (Assael & Waldstein, 1982). The belief in the efficacy of parent involvement has received legal sanction in the mandates of P.L. 94-142. The law requires that we provide an opportunity for parents to participate in the planning of educational programs for their children through the joint development and execution of an Individualized Education Plan (IEP). HCEEP projects are also required to "contain plans for meaningful involvement of parents and other family members" (Federal Register, 1975).

A great deal of literature has been developed relating to the value of parent involvement as a general educational component. This paper addresses parent involvement programs as they are designed and implemented in HCEEP projects. A definitive answer to the numerous problems that arise in developing an individualized and effective parent program is not given; no easy solution is available. However, some general guidelines for all programs are available. The paper presents a discussion of the rationale for parent involvement programs, ideas on parent needs assessments, types of parent programs currently in use and an overview of parent evaluation procedures.

## Rationale for Parent Involvement

The idea that parents should be meaningfully involved in the planning and development of programs for their children seems both simple and basic. After all, being a parent implies becoming an advocate, a preacher, a lawyer, an accountant, a teacher, a nurse and much more. Parents hold their children's guardianship, their proxy, their power of attorney, their custody and their care. They are the child's representative in an adult society and the protectors of their legal and human rights. Parents have the responsibility for their children's care and development 24 hours a day, 365 days a year for as long as they remain dependent. True, some of this responsibility is delegated to others for certain periods of time, e.g., the physician for acute medical treatment or the teacher for formal instruction; but it is the parent who must assume responsibility when the treatment is complete or the school day ended.

It is well established that efforts of school or clinic provide better results if parents are involved (Bronfenbrenner, 1974). The Comptroller General of the U.S. (1979) reported to Congress that:

> Early childhood experts generally agree that the family is the primary influence in a young child's development. Research shows that the most effective child development programs have been family-oriented programs that have meaningfully involved parents in educating their children. (p. 10)

Parents are integrally involved in the education of their children; partners to both the program staff and their children. They can provide undeniable assistance to a program when their participation is meaningfully designed. Some of the obvious ways a program might be improved through parent involvement are:

1. Parents can provide useful information about their child. They often have information about motivation and behaviors that will not otherwise be available to the teacher or therapist.
2. Involvement of the parents will facilitate transfer from school to home and help to insure that there is follow-up of school-learned skills in the home and after graduation.
3. Cooperative efforts between home and school can accelerate the rate of learning. Fredericks, Baldwin and Grove (1976) report that adding meaningful parent involvement to the school program will almost double the rate of acquisition of skills.

However, there are conflicting opinions on the efficacy of parent involvement programs. Stile, Cole and Garner (1979) point out that literature on parent programs demonstrates attrition rates from 10 to as high as 70%. Wherein lies the problem? Data on the efficacy of parent involvement exists. Parents of handicapped children certainly have special needs that a HCEEP program could satisfy. Needs specifically relating to the specialness of a child are always present. However, two problems stand out. One is simply a matter of attitude. We tend to think of doing something for the parents rather than accepting them as team members. If we approach the question of how to involve parents from their position as team members, it becomes clear that parents can become involved in all parts of our program and can, indeed, extend our services. The other problem relates to the conception of meaningful involvement. It is much easier to think of things to do for parents or to have parents do, than it is to determine the usefulness of that activity for the parents and their children. For a parent program to be meaningful, it must have a trilateral benefit--to the parent, the child and the program as a whole.

Professionals needn't worry about getting parents involved in the life and education of their children. They already are--to an extent beyond the professional responsibility or capacity of most educational programs. What we need are thoughtful and useful means of including parents in the structured education of their children.

## Assessing Parent Needs

The needs assessment is the first step in planning an individualized educational program. For a parent program to be beneficial, it must begin with an accurate assessment of parent needs and then coordinate the services within a realistic time-frame for the participants. Each parent comes to a program with a different degree of understanding, knowledge and acceptance of his/her child's disability and varying opinions on their role in a program's educational structure. Because of the individual differences among parents and families, they will need different types of services, and/or different degrees of involvement in the various types of programs.

An effective needs assessment should establish a framework to guarantee that the parent program does not exhaust the limited energy of the parent; parents, after all, should be the consumer not the consumed (Turnbull & Turnbull, 1978). Assistance must be judiciously implemented and tuned to the schedules of the parents. The parents of a disabled child have the responsibility of full-time care of the child, but they also have other responsibilities. They are not always able to schedule their activities around the hours of a program. Also, certain disabilities require rather strict scheduling in order to make certain that all of the care requirements are met. Intervention programs must be designed to compliment these schedules, not disrupt them. The needs assessment should insure that the interventions remain beneficial and not become a hindrance or additional problem for the families served.

The needs assessment process must take into consideration that parents may not possess the knowledge needed in the new situation, so it may become necessary to provide some information to help them participate meaningfully in the assessment process. The assessment, if administered successfully, will then provide the basis for evaluation of the parent involvement component. It must be remembered that the needs of the family will change; therefore, the needs assessment should be continuous. The initial assessment may be quite formal; after that an informal, continuing process might be utilized.

An example of a model which demonstrates the diversity of parent needs and the process of matching these needs with existing services is the "Mirror Model of Parental Involvement in Public Schools" (Kroth, 1980). This model mirrors professional services for parents against parental services for professionals and parents. The model identifies the types of professional services that are needed by all, most, some and a few parents and these are mirrored against the types of services all, most, some and a few parents can provide. (See Figure 1.) Although the specific items listed relate to public school participation, the concepts are applicable to any parent involvement program.

There are numerous instruments for assessing parent needs. For more information, refer to Gathering Information From Parents (Vandiviere & Bailey, 1981), WESTAR Series Paper #3, Individualizing Parent Involvement (1979) and Caldwell's Home Observation For Measurement Of The Environment (Caldwell, 1979). These publications should aid both parents and project staff in developing useful need assessment processes.

Planning of parent learning experiences should be a mutual undertaking between the parent and the program staff. The parents should be involved in the process of identifying their needs, formulating their objectives, identifying resources, choosing activities and evaluating their progress. This involvement should lead to a commitment, a true assessment of need and therefore, to higher motivation.

## Types of Services

Among the many ways of meeting the needs of parents, four types of services are most widely utilized. They are: parent education, direct participation, parent counseling and parent-provided programs.

### Parent Education

Although a parent education program can take a variety of forms and cover different materials, information included in most parent education programs falls into the following categories: what to expect from a conference, how to participate in planning, information on normal infant growth and development, specific knowledge about their child's disability, community resources and skills to provide the special care needed by the child.

What to expect from a conference. One of the first activities on the agenda for parent education is an awareness of what to expect from an interview or conference. How do parents prepare for an interview? What materials should they bring to the interview with them? Perhaps even more important, what questions should they ask about their child, about the program, about expectations and about other services? The Umbrella for Families Project (Sweet & Humphrey, 1980) targeted this problem by assisting parents to develop a "diagnostic notebook." This is designed to organize the basic information needed by professionals about the child and family--such as social/family history, health and medical history--in one place, so that it will be available for future sharing. For more information, contact the project: P.O. Box 1054, Moses Lake, WA 98837.

Figure 1

MIRROR MODEL FOR PARENTAL INVOLVEMENT IN PUBLIC SCHOOLS

| | |
|---|---|
| Few | In-depth workshops/or therapy groups. |
| Some | Parent Education Workshops. |
| Most | Placement Committee meetings, IEP conferences, parent meetings on how to participate, class handouts, phone calls, home visits, reporting conferences, information on workshops available. |
| All | Information on consent to test and place, information on criteria to place, due process procedures, information on tests and other school records pertaining to child, information on how to participate on placement committees and IEP conferences, information on services available. |
| All | Information on child and family that pertains to educational programming. Information on needed services. |
| Most | Input into placement decisions and IEP decisions, assistance on field trips, support on agreed programs, feedback to professionals. |
| Some | Parent advocates for other parents, parent advisory groups, task force members on curriculum, etc., volunteer help in classrooms. |
| Few | Parent-to-parent programs, workshop leaders. |

Note. From Kroth, R.L. Strategies for Effective Parent-Teacher Interaction: A Guide for Teacher Trainees. Albuquerque, NM: Institute for Parent Involvement, 1980. Reprinted by permission.

How to participate in planning. The law requires that parents participate in the development of their child's Individual Education Plan (IEP). A number of publications have been prepared for teachers on this topic (Morgan, 1980; Sedlaek, 1979); workshops have been presented and the contents of special education teacher preparation courses have been modified to prepare teachers to develop IEPs. Unfortunately, there has not been the same kind of effort to prepare parents for their role in the planning process. Parents are involved in developing IEPs, but for the most part their involvement is minimal. Usually the teacher prepares the list of goals and presents them to the parents for approval. The Madison public schools have received funding from U.S. Special Education Programs to develop, document and disseminate a model for involving parents more actively in the writing of IEPs and in setting goals for their children. They suggest that such a model, if well established at the early education level, might have carry-over value to the regular school (Gruenewald, Miller, & Vincent, 1980).

One source for helping parents prepare for their role in planning is the workshop for parents developed by the Council for Exceptional Children. This two-hour training package includes a filmstrip and a 64-page guide designed to help parents become productive participants in the IEP process (Nazzaro, 1979). Another is a workshop developed by Stevens (1980) which is available from the Parent Involvement Center, Albuquerque Public Schools, 1700 Pennsylvania NE, Albuquerque, NM 87110.

Information Concerning Normal Growth and Development. Very little information is provided young parents in the United States about child growth and development. Although it is important for all parents, perhaps it is not as necessary for parents of normal children as these parents receive an instant course from their child. But what if the child should for some reason deviate from normal? How then can parents chart the development of their child? How can they compare this with the normal? It will be necessary for early education programs to provide this information. Beside providing information to parents, HCEEP projects often have to interpret the growing amount of information available through popular books and media. Not only does the educational jargon need to be translated, but the knowledge of child development takes on a different perspective when used as a comparison to a handicapped family member. The HCEEP program considers it important enough to include information on normal child growth and development as a requirement (Federal Register, 1975).

Specific Information About the Child's Condition. A common complaint of parents is that they had difficulty finding out just what was wrong with their child. Such reports as, "It was two years before we were told that our child had Down's Syndrome" (Porter, 1978, p. vi). Or, "Within the first two months I noticed differences. By six months, I was alarmed. When I asked the doctor, he told me she was within the normal range for development" (Smith 1978, p. 1). Or, "The child is perfectly normal, but the parents are obviously neurotically anxious" (Roos, 1978, p. 15). Often the initial diagnostic encounter is the only information the parents receive, and they may be more confused after the encounter than they were before, leaving with a new label that they do not understand and that does not lead them to the needed services. Judy Burke (1978) in an article entitled, "Face to Face in Times of Crisis and Over the Long Haul" describes very dramatically how she had to discover on her own that "Spastic" needed to be translated into "Cerebral Palsy" in order to find the services that her daughter needed.

If parents are to serve as their child's advocate for needed services, they will need to have a working knowledge about the disability their child has and the course the disability is likely to take. To understand all of this they will need to learn some of the technical terminology and professional jargon related to that particular condition.

What are the Community Resources? In a parents' symposium, held as part of the 1980 HCEEP Project Directors/Division of Early Childhood Council for Exceptional Children meeting, the participants identified "difficulty of finding health/educational services for their handicapped child" (Buffington & Assoc., 1980, p. 39) as one of the major problems they faced. They listed as their number one recommendation:

> Establish a clearinghouse for parents, health professionals and educators to reference and cross-reference programs and services available in particular areas for the handicapped and their families (Thomas Buffington & Assoc. 1980, p. 3.9).

The parent will need knowledge, not only about what resources are available, but about what each has to offer and how to use them for the most benefit with the greatest economy of time and money.

A parent program has a wealth of available information to help identify community resources. Information sharing among HCEEP projects is a basic resource accessible to all programs. National organizations such as CEC, March of Dimes and Easter Seals often have resource information centers. And publications on parent involvement (e.g., Coletta, 1977) can provide useful hints on ways to locate additional community resources.

Special Skills Needed to Provide Care for their Child. The most common subject of needed parental education is in the area of specific skills for the care of a disabled child. In some cases these skills will be quite technical, and parents must learn sophisticated procedures. In others, the care is relatively routine, but parents will need certain information in order to best serve as case managers for their child. As Buscaglia (1975) points out, "Since they will be doing something for their child anyway, would it not be advantageous, for all, to teach them the right way?" (pp. 269-270). Some of these skills can be taught didactically, but others will require direct participation of the parents in the treatment program.

During the past 12 years, the HCEEP programs have developed a number of excellent resources dealing with many of these subjects. A partial listing and description is available in Parents as Teachers of Their Handicapped Children: An Annotated Bibliography (Wolery, 1979). Other sources of information are: What's Where? A Catalog of Products Developed by HCEEP Projects (Brookfield, Waldstein, Pelz, & LaCrosse, in press) and the Fall, 1981 Edition of Special Education Materials (LINC Resources, Inc., 1981). Another listing of HCEEP-developed products will be printed as part of the project survey now being conducted by Roy Littlejohn and Associates in Washington, DC, under contract with U.S. Special Education Programs.

Parent Education Workshops. It should be evident from the foregoing discussion that much of the parent education program needs to be individualized, but there are a number of parent information needs which can be met through group instruction. The content and timing of such group programs should be carefully planned to meet the needs of the particular parents involved.

It cannot be assumed that knowledge in one area means knowledge in another, nor that formal instruction will automatically meet the need. In a parent group for deaf-blind preschoolers, for example, it became evident early on that one of the mothers, a nurse, had a great deal of knowledge about the etiology, effects and prognosis of rubella. Within a short time, however it also became evident that she knew less about how to teach her child to eat, dress or toilet than did the other "less knowledgeable" mothers. She reported that she received a great deal of assistance from talking to the other mothers about how to deal with these specific problems. This experience is just one illustration of some of the advantages gained by offering parents the opportunity for group activity. This aspect of the parent involvement program is discussed more fully in the section on parent-provided programs.

**Direct Participation**

Direct participation refers to the involvement of parents as teachers, teaching assistants, classroom volunteers--as partners with professionals in the delivery of educational programs for their child. In the past, there have been a number of problems associated with this approach. Karnes and Esry (1981) report that until recently, work with parents was limited to two or three parent-teacher conferences a year in which the teacher talked and the parents listened. Schulz (1978) stated that there was a reluctance on the part of teachers to accept the abilities of parents, and she describes her own involvement with the schools as follows:

> My suggestions were never welcomed. I was enthusiastically encouraged to help with the field trip to the airport and to make popcorn balls for the Christmas party. And yet, during periodic visits to the classroom, I saw teenagers wasting valuable time taking naps, obese children constantly snacking, my son learning things he had known five years before. (p.31)

In some cases, the approach to direct participation was based on the assumption that parents should normally provide most of the early instruction for their children, and if they do not, then the parents are themselves in need of intervention. However, an increasing amount of evidence is mounting to indicate that support--not intervention--for parents is most often called for in these situations (Tjossen, 1976).

New Approaches. The last decade has witnessed a variety of new approaches to direct involvement of parents in early education of the handicapped. For example, one emerging pattern emphasizes working with child and parent together and focuses on improving parent-child interaction rather than working with either the child or parent alone (Ora, 1971). This technique involves behavior modification methodologies. The advantages of such an approach are that behaviors which are causing problems are dealt with directly, parents learn skills of behavior management that are useful, and there is instant success which helps to relieve tensions. The success of this type of program is readily measureable in terms of change in child behavior as a result of change in parent behavior, and the results have a good chance for continued and expanded success as the changes in parent-child interactions are mutually rewarding.

The Portage Project (Shearer & Shearer, 1972) provided a home teaching program, directly involving parents in the education of their own children by teaching the parents what to teach, what to reinforce and how to observe and record behavior. The children in this project made statistically significant measureable gains in IQ, language, academic development and socialization. A follow-up study showed that the gains were maintained. The staff of this project believed that the success of their work was due to:

- Setting goals at a level the child and parent could accomplish within a short time, for instance, a week.
- Providing a model for parents; showing them, not just telling them, what to do.
- After modeling, allowing the parents to take over and work on the same activity with the child while the teacher observes.
- Reinforcing the parents, letting them know they are doing it right.
- Remembering that parents are not the same. It is as important to individualize for parents, based on their present behavior, as it is to individualize for the child based on his/hers.

- Involving the parents in planning appropriate goals for the child. (Shearer & Shearer, 1977, p. 230)

Fredericks, Baldwin and Grove (1976) describe three ways in which they have successfully involved parents in teaching their child: (1) The lunch box data system, in which the parents conduct instruction similar to that being conducted at school; (2) The modified lunch box system, in which parents conduct instruction at home that is not being given by the school; and (3) The volunteer system, in which parents are volunteer workers at the school and through that experience acquire the instructional capabilities to teach their child. Success in all three of these programs depended on selecting activities which parents are likely to succeed in, and breaking the skill to be taught into small parts.

Provisions for the direct participation of parents have also been included in many of the new educational programs for handicapped and high-risk infants, as shown in a 1979-80 survey of infant projects funded by the HCEEP (Karnes, Linnemeyer, & Schwedel, 1981). Formal parent needs assessments were conducted in 20 of 25 projects responding to the survey. Twenty-two projects offered parent training, and an equal number encouraged parents to work at home with the child. Working with infants in a group setting was an option in 18 of the projects. More than two-thirds of the projects had set up libraries for the parents so they could obtain information about handicapping conditions and activities for the home. Counseling services were made available to parents in 19 projects, and just over half of the programs offered advocacy training. (Some parents chose not to participate or to participate only to a limited degree. The reasons given for lack of involvement were: time constraints because of job, just not interested, lack of transportation, difficulty arranging for a baby sitter, and pressing family problems.)

Programs with Fathers. One recent development is the attention given to direct participation by fathers in early education. A number of studies, (Cummings, 1976; Peck & Stevens, 1960) indicate that the entire family, fathers as well as mothers, have difficulty adjusting to the birth of a handicapped child. Neifert and Gayton (1973) found that if fathers did not give active support to the instructional efforts of the mother, the child would not take the program seriously, and the mother's efforts would likely fail. Yet until very recently little has been done to provide the opportunity for fathers to participate.

Delaney (1979) provided an intervention program for fathers of handicapped infants at the Experimental Education Unit of the University of Washington and found that attachment between fathers and their handicapped infants was increased by improving the father's awareness of his son or daughter's development. The project has since been expanded to include siblings and extended family members, as well as fathers, in a replicable model. Materials from the project will be available for dissemination as they are produced (Dubois, 1980).

The UCLA Intervention Program developed a father involvement program on a trial basis in 1981. It was so well received that it was extended until the end of 1982 (Kehr & Miller, 1981). Some of the program features which contributed to its success were:

1. Sessions were scheduled on alternate Saturdays.
2. The fathers showed a genuine interest in working with their children.
3. Provisions were made for discussions away from the children. A half-hour of each session was set aside for this activity with fathers selecting the topics.

4. The activities were essentially the same as provided during the regular program.
5. The number of planned field trips proved to be too demanding, and were reduced.

The indications from this program are that the fathers do want to work directly with their infants. Mothers reported that fathers were more involved with the care of the children at home after the initiation of the program.

Project REACH, in Northhampton, Massachusetts, (Karnes, Linnemeyer, & Schwedel, 1981) also provides for the involvement of fathers. The project staff consider involvement of fathers as natural and expected. Home visits are scheduled, whenever possible, so that both parents can be involved in the demonstrations, goal-setting and teaching activities. In addition, specific provisions are made for fathers, including discussion and support groups, male staff for individual counseling, and informational materials designed especially for fathers.

The changing structure of the American family suggests that several adjustments must be made to allow for direct parent participation. Today the "traditional" American family including a working father, stay-at-home mother and two children represents only seven percent of the nation's two-parent families. Of married women with children under six, 43 percent work, and the number of single-parent families has increased dramatically during the past decade (U.S. News and World Report, 1980). These changes will require some ingenuity on the part of program planners to provide opportunities for meaningful participation by parents. But the results seem to well warrant the effort.

Benefits of Direct Involvement. A number of studies report the benefits of direct participation to the parents themselves (Garland, Swanson, Stone, & Woodruff, 1981) and to the children involved. For instance, Badger (1977) reported on a research project conducted by the Cincinnati Maternal and Infant Care Project in which 12 mothers age 16 and under and their infants were provided weekly classes to stimulate the infants' development by supporting the mother's role as primary teacher. A comparison group of 12 mother/infant pairs was matched and followed over the course of the 18 months of the program. The infants in the comparison group began to fall behind early in life and were indeed in "jeopardy." This was not however the case for infants of the mothers who attended classes.

It has become evident from this and other studies that direct participation from parents in the education of their children has not only improved the success of the programs, but that unless the parents were involved and the desired skills were being taught or reinforced in the home, as well as in school, the results at school were less than optimal. In fact, the lack of participation might actually preclude the development of the desired child behavior.

## Parent Counseling

Few individuals plan to become parents of a handicapped child. When it happens, hopes, aspirations and lifestyle are changed; energies are redirected. Questions about the child's health and development need to be answered, and new, unrehearsed feelings need to be dealt with. (For example, one of the major problems a parent faces--when confronted with the sudden new relationship with society and friends occasioned by becoming the parent of a disabled child--is that many of the unacceptable attitudes and prejudices that become evident in others are the same as he/she held prior to the event.)

A number of writers (Drotor, Baskiewicz, Irrin, Kennel, & Klans, 1975; Miller, 1968) suggest that parents of handicapped children must go through a process of adjustment, and Olshansky (1962) suggests that a parent's response to having a mentally handicapped child is one of "Chronic Sorrow." Dunlap (1979), on the other hand, reported that the vast majority of families

interviewed in a study of 53 deaf infants and children did not perceive the handicapped members as having a substantial negative influence on their families. When the handicapped child was seen as having affected the family, it was more often in areas such as trips, vacations, visiting, shopping, going to movies or whether the mother will work. The study also indicated that time demands, physical demands and money problems were often listed as important factors.

Coping Patterns. Of course, there are as many ways of coping with traumatic experiences as there are people who must face such an experience. There will be those who accept it as matter of fact. They will choose alternative ways of coping and look for constructive ways to deal with the situation. There will be those who will deny that a problem exists, who will suppress their feelings. And there will be those who will be overwhelmed with feelings of guilt, shame, self-pity, anger and despair. Most individuals will fall somewhere between these extremes. The reaction that an individual makes will change over time, depending on the progress of the child, the support the individual receives and the changes in his/her life situation.

There are a number of variables which may affect the degree and type of parental reaction to having a handicapped child. Among them are: the type of disability and the parents' attitude about it, the socio-economic status of the family, the birth order of the child, and the size of the family.

Parents need to be reassured that they can raise their handicapped child . They need to know what the problems are related to the child's disability and how to solve them, what services are needed and available and how to access them; and they need varying degrees of help to sort out their feelings. Sometimes this is no more than an interested listener.

Criteria for Successful Counseling. The counseling process, which usually begins when the parents take the child to a professional or clinic for initial diagnosis, can be extremely confusing and upsetting for the parents. A number of techniques have been identified which can contribute to the success of the counseling process. Solnit and Stark (1961) warn that while in shock, parents have an impaired ability to recognize, evaluate and adapt to reality; and they suggest that professionals communicate the findings about the child's condition several times.

Davidson and Schrag (1969) reported that recommendations made during child psychiatric consultations were more likely to be followed if:

- Both parents were present for the consultations.
- The parents had discussed their child's problems with others.
- They agreed with the professional's diagnosis and evaluation of the problem.
- Families had to wait less than half an hour to see the psychiatrist.

The authors point out that unless the parents understand and accept the information which is presented, very little can be done for the child.

From a review of the literature on research in counseling with the handicapped, Jim Leigh (1975) concluded that:

1. Professionals need to devote much more attention to the format and content of initial diagnostic interviews with parents. Both the results of research and the comments of parents...clearly demonstrate that parents are often confused and dissatisfied with the information, or lack of information, about the problems of their child.

2. The term shopping behavior as applied to parents who visit many professionals is both overused and misused, since the very few parents who qualify as shopping parents are seeking valid assistance and not merely a different diagnosis. Even if a great number of parents do engage in shopping behavior, perhaps professionals should view that behavior as a reflection of the quality of the services offered rather than as an indication of the parents' denial of reality.
3. Research indicates that professionals often underestimate the importance of the parents' attitudes.
4. Parent counseling is receiving an increased amount of attention as studies and program descriptions have indicated that parents must play an essential role in efforts to remediate their child's problems. In fact, the results of many studies indicate that parent counseling may be more beneficial in many situations than direct therapy or remediation with the child. (pp. 60-61)

Some indicators of success of a counseling effort are: parent satisfaction, the degree to which recommendations are followed, the ability of parents to cope with the overall adjustment of having a handicapped child in the family, the degree to which the needs of the rest of the family are filled, the parents' own adjustment or readjustment to life, the ability to discuss the problems, and the realism of the content of that discussion.

It must be recognized that some disappointment, fear, anxiety, anger, helplessness, pain, disbelief, shock, self-pity, resentment and confusion are normal under the circumstances. The degree to which a program can assist individuals to cope with these emotions, and the many physical demands placed on them, and still be able to function is a real measure of success of that program. The program must be larger than "parent counseling"; a handicapped child places stresses on the entire family, and the needs exceed those usually addressed in counseling.

### Parent-Provided Programs

Parents of handicapped children can obtain moral support, information and a new perspective by involving themselves with other parents who have had or are having similar experiences. Of the ways that parents serve other parents, the best known are parent organizations, parent-to-parent programs and parents as advocates.

Parent organizations. Parent organizations exist for most types of disabilities. These organizations can and do provide an opportunity for parents to gain the awareness that they are is not alone. They also provide a resource for information on the specific disability, in terms that are meaningful for the parent. If a local chapter is not available, most of the national organizations provide information for developing participation at the local level. Involvement in such a program provides an opportunity for a great deal of flexibility in expression. Some parents will be able to provide leadership, others will be active doers and still others will be passive listeners.

Parent-to-Parent Programs. A parent-to-parent program is one in which parents of disabled children (pilot parents) help other parents who have recently learned that their child is disabled. New parents are served by contact with others who have faced the same problems. They can talk to someone else who can understand the feelings of isolation and doubt and who can assist in finding needed services.

To be a pilot parent requires that a parent has made an adequate adjustment to being the parent of a disabled child, and that he/she has sufficient time and energy to devote to the project. Being a pilot parent is not for everyone, but the opportunity to contact such a group should be available to all new parents of children with disabilities.

A manual for developing a pilot parent program is available from the Greater Omaha Association for Retarded Citizens, 3212 Dodge, Omaha, Nebraska, 68131.

Parents as Advocates. The effectiveness of parents as advocates is well documented. During the past 30 years there has been a growing sophistication and awareness on the part of parents of the handicapped. The increasing reference to the rights of the handicapped in literature, legislation and litigation all bear witness to this change. Today many of the services parents were fighting for a short time ago are taken for granted, and perhaps some of the urgency for involvement as viewed by the parent is not as intense as it was earlier. But it is still extremely important that vigilance be maintained, or these previous gains could be lost.

The parent of a handicapped child can speak much more emphatically about his/her child's unmet needs than can the professional. As constituents in need, their voices are heard in a different way by the legislators. The partnership between parent and professional becomes important in providing support to each other in obtaining the best services for those who need them most.

## Evaluation

Evaluating a parent involvement program involves determining the value of that program to the parents who receive it. Ideally, to assess the value of the program would require comparing it with another program of known value or at least comparing the changes in program recipients with others who have not received the program. Both of these approaches present difficulties. There are seldom comparable programs of proven value and programs are selected or tailor-made to meet the individual needs of parents, making control groups difficult to locate.

There are two basic issues regarding the evaluation of parent involvement programs. One relates to the role of the parent in planning and evaluating the overall program. The second relates to the effectiveness of the activities planned for the parent component.

### Parents as Evaluators

HCEEP projects are required to provide for the involvement of parents on project advisory committees. They have confirmed their genuine belief that parents should be involved in planning by generally exceeding this requirement. This belief is well expressed by Vincent, Laten, Salisbury, Brown and Baumgart (1980) when they say, "Parents are the major consumers of services provided to handicapped children; as such, parents should be the major evaluators of these services" (p. 177).

The role of parent as evaluator must be separated from reporting on individual parent satisfaction. For parents to be effective as program evaluators, they will have to step back and look objectively at the overall parent involvement program. The parents' activities in program evaluation should lead to involvement in program planning. Not all parents will be interested in actively participating in overall planning for the program in which their child is enrolled, but they should, at the least, be offered the opportunity to respond to any proposed major program changes.

How to involve parents meaningfully in evaluating services which they or their child are receiving is not an easy problem to solve. There are a number of issues which complicate the effort. Among them are the problems related to fears of losing a service--which might have been extremely difficult to obtain for their child--if the parents are too critical. A format for involvement should be established which will provide for positive input, so that needed changes can be identified and mutually agreeable solutions developed without putting either the parents or the administration on the defensive. An atmosphere of mutual trust is a prerequisite for meaningful parent participation in planning.

Another problem relating to parents as evaluators is the question of the validity and reliability of parent responses to questionnaires. Schnelle (1974), in a follow-up study of counseling service, showed a lack of correlation between what the parents reported was happening and what was actually happening. This points up the need to make reliability and validity checks at least on a random sample of questionnaire reports before accepting results.

Although these problems are pervasive, the importance of parent involvement in evaluation dictates that we continue to seek ways to improve opportunities for parents to meaningfully participate. To accomplish this requires that the problems be resolved.

## Effectiveness of Parent Involvement

The effectiveness of the parent involvement program is a measure of the degree to which the objectives of the program have been met and how well these have satisfied the identified needs of the parents. Among the ways to evaluate the effectiveness of parent involvement are: parent satisfaction, changes in parent knowledge, skill and attitudes, the degree to which services are utilized, the degree to which the knowledge or skill is used, and changes in child behavior as a result of changes in parents' behavior.

Parent Satisfaction. The evaluation of the parent involvement program begins with the needs assessment. Much has been said about the individual differences of parents and their changing needs over time. The assessment of parent satisfaction is an expression of the degree to which needs were correctly assessed and met. Often, the information collected on parent satisfaction relates to satisfaction with the overall program and not satisfaction with the parent involvement program per se. This information is important but should be interpreted in the proper context and not confused with responses to planned parent activities. Among the ways of assessing parent satisfaction are: interviews, questionnaires and diaries.

INTERVIEWS: An interview provides for personal interaction between two or more people. It can be guided by predetermined questions and offers the opportunity for the interviewer to pursue interesting responses.

Some advantages of interviews are:

- They do not require a written response on the part of the interviewee.
- They have a higher rate of response success than a questionnaire.
- The interviewer can clarify the questions to insure that the respondent understands them.
- They allow for interviewees to explain their response and also the degree of their feeling about a particular issue.

Disadvantages:

- They are time-consuming.
- The presence of the interviewer may influence the responses.

- The answers may not be thought through, since the interviewer is present and this indicates that an immediate response is required.
- They require trained interviewers.

QUESTIONNAIRES AND RATING SCALES: Questionnaires and rating scales are instruments requiring a written response.

Advantages are:
- They permit anonymity.
- They permit the person opportunity to think about answers before responding.
- They can be administered to many people simultaneously.
- They provide more uniformity than interviews.
- The data is easier to analyze than interview data.

Disadvantages:
- They do not provide the flexibility of interviews.
- People are usually better able to express themselves orally than in writing.
- Reliability and validity of parents' responses are not high.
- The percentage of responses is usually lower than for interviews.

If there are a variety of concerns, most of which can be covered by asking straightforward questions, a questionnaire will work. You will need to allow time to develop a questionnaire for your particular needs. The questionnaire will need to be constructed, the questions checked to remove ambiguity and a reliability and validity check run. (For detailed information on development of questionnaires, refer to Staff Development: A Systematic Process by Jeffri Brookfield.)

There are a number of scales to rate responses to a questionnaire. An agreement or Likert scale consists of a group of statements which are either favorable or unfavorable. The respondents are asked to report the intensity of their agreement or disagreement with the statement on a 5-point scale: "Strongly agree", "agree", "undecided", "disagree", "strongly disagree". An agreement scale is useful when you want to determine both the direction and the intensity of a person's attitude.

The ECE-SMN Center at Arizona State University utilizes an agreement scale (Roberts, 1981) to determine parent satisfaction. Examples of the questions asked are as follows:
- The staff members who visit my home are informative and friendly.
- I feel there is a positive change in my child since entering the ECE-SMH Program.
- I feel comfortable talking with staff members.

For more information on this scale and its use, contact: Dr. Thomas Roberts, ECE-SMH Center, Department of Special Education, Arizona State University, Tempe, AZ 85281.

The Semantic Differential or Osgood Scale consists of a series of adjectives, usually around 10, and their antonyms listed on opposite sides of the page, with seven "attitude positions" in between. The Semantic Differential is usually regarded as a good tool for measuring people's positive or negative feelings toward the attitude objective. Project Pre-Start of Loyola University has developed such a scale for parents of high-risk infants. For more information on this scale, contact: Pre-Start Program, Loyola University Stritch School of Medicine, 2160 South First Avenue, Department of Pediatrics, Maywood, Illinois 60153, and ask about the Schmerber Attitudinal Survey for Parents of High-risk Infants. For information on the construction of attitude scales, the reader is referred to Edwards and Porter's Attitude Measurement (1972).

PARENT DIARIES: Parent Diaries are self-reporting instruments which provide descriptions of activities, experiences and feelings written during the course of the program. Daily or weekly recordings of significant events and reactions to the events can be analyzed at the end of the program to determine reactions to certain components. They may also reveal attitudinal change. Their advantage is that they can provide a great deal of personal information which might not otherwise be available; their disadvantage is that they are difficult to interpret objectively.

Changes in Parent Knowledge, Skills & Attitudes. Criterion-referenced tests, designed to determine if the degree of competency desired has been met, can be developed to assess the knowledge gained in a parent education course. Pre and posttests will provide a measure of change. Posttests alone can provide information regarding parent knowledge, but it cannot be assumed that the information came from the training on the basis of one posttest alone.

The SEFAM program at the University of Washington offers an example of use of criterion-referenced tests. This program is designed to study what happens in families and to investigate better ways to insure positive outcomes from activities and relationships that affect the young handicapped child. Guided by the overall objectives of the program, the staff selected a number of instruments to measure changes in family, both in father and mother and in father/child relationships. From the results of these tests, individual objectives are established for the purpose of modifying relationships in a positive manner. Posttests are administered at the end of the year to measure success in bringing about these changes. The areas for selection of objectives for each parent and the tests used to identify them are illustrated in an "Assessment Matrix" figure. For more information on this program, contact Dr. Rebecca Fewell, Director, SEFAM, University of Washington, WJD, Seattle, WA 98195.

The parent/family component of the FINIS Project in Marshalltown, Iowa has two key elements--family life education classes and family system counseling--which are evaluated with pre/posttesting. Data on parental attitudes are assessed using a parent attitude scale. At intake, parents are asked to fill out a pretest covering the information which will be taught during the eight-week family course. Following the completion of the parent classes, a posttest using paraphrased items covering the same information is administered. For more information on this program, contact Damon L. Lamb, Director, FINIS Project, Area Agency #6, 2101 12th Avenue, Marshalltown, IA 50158.

A number of instruments have been developed by HCEEP projects to assess changes in parent knowledge, skill and attitudes. Descriptions and samples of these instruments are available in Gathering Information from Parents (Vandeviere & Bailey, 1981).

Direct observation or performance tests are procedures for evaluation of skill performance. Provisions need to be made for observing the parents performing the required skill, and feedback must be provided to them so they will know when they have reached the level of skill required. Mini-teaching programs utilizing audio and videotapes for self-correction are also well suited to this purpose.

Degree to which Services are Utilized. No matter how attractively packaged or how logically sound a program seems to be, it will not have any validity unless it is used. An activity which was popular in one part of the country or with a particular group may not be effective with another. Therefore it is important to fit activities to the interests of the individuals you are trying to involve. Although we might equate the amount of involvement with satisfaction in terms of the total program, this could be a serious error when applied to an individual because there may be a variety of good reasons why an individual parent might

choose not to be involved at a particular time. The requirement is that the opportunity should be available to all parents, not that they all use it. The parent should have the choice, for as Winton and Turnbull (1981) reported, noninvolvement at certain times may be a great contribution of the program to the parents. If parents are not motivated or interested, forced participation will have little or no benefit.

Degree to which Knowledge or Skill is Utilized. There are several difficulties involved in measuring utilization of knowledge and skills, since there is no easy way to observe what goes on between the parent and child while the child is at home. One complex problem involves parents' attitudes toward childrearing and their willingness to change. Anastasiow (1981) states:

> Childrearing attitudes are values and as such are resistant to simple intervention strategies. Some minority groups feel that attempts to change their childrearing strategies are attacks on their culture rather than attempts to facilitate their children's development. In some cases, intervention may actually be an attack on the culture, and great care needs to be taken to avoid such a circumstance. (p. 4)

However, there are areas of learning that can be observed, for example, in the care and use of prosthetic devices. Does the child have the hearing aid on when he/she comes to school? Is it on correctly? Is it working? There are a host of other behaviors of this type which can be directly observed, e.g., the parent rewards appropriate behavior, initiates conversations with child, gives child verbal instructions which are developmentally appropriate. These observations will not tell you whether the skills are used at home during out-of-school hours, but it will provide information on the observable utilization of the skill. An additional measure is how the parents feel about the situation. Are they more comfortable or sure about their ability to perform the task?

HCEEP projects use three basic methods to evaluate the extent to which knowledge and skills are utilized: direct observation in the home, observation of parent in a clinical setting and self-report measures.

The Portage Project in Portage, Wisconsin focuses on effective parent involvement to facilitate long-term early childhood intervention and uses direct observation of parents in a home environment as their basic parent evaluation tool. For more information, contact the Portage Project, 626 East Slifer Street, Box 564, Portage, WI 53901.

Observation in a clinical or classroom situation offers a controlled examination of parents' skills. For information on this evaluation methodology refer to the work of Dr. T. Berry Brazelton or to the numerous publications of Teaching Research Infant and Child Center Data-based Classrooms, Todd Hall, Monmouth, OR 97361.

Direct observation using either of the above settings is the best method of collecting data. However, self-report data will suffice if no other form of evaluation is available. The important factor is to obtain some measure of parent skills and likewise be able to assess the efficacy of the parent program.

As an example, Project FINIS in Marshalltown, Iowa assesses the nature of interaction between each of the parents and their handicapped infant with a direct observation, pre/post methodology. Parents are assessed at intake, and after 3 months the interaction patterns are assessed again in order to determine changes in primary caregiver and handicapped infant behavior. Data is collected on two major elements of family systems: the family network and family interactions. A profile of family interactions is obtained from a filmed 30-minute structured interview. This same structured interview is also used as a posttest following family system services. The interactional analysis is used to collect data on communication skills, problem-solving skills and alliance sequences.

The results of these activities are analyzed to demonstrate program impact on: knowledge of infant development, communication and problem-solving skills of families, infant-caregiver interactions, knowledge of the developmental characteristics of families, parental attitudes and family capacity to achieve goals.

A number of publications will be available from this project. For additional information, contact: Damon L. Lamb, Director, FINIS, Area Education Agency #6, 2105 12th Avenue, Marshalltown, IA 50158.

Changes in Child Behavior. The ultimate goal of parent programs, of course, is change in child behavior. The children are being assessed, and hopefully there are positive changes in their behavior. How do we determine to what extent our efforts with parents have brought about these changes?

Some activities are directly measureable, such as in-home programs where specific lessons are taught by parents and the child is evaluated on the content of these lessons, or in behavior management training sessions involving parent and child where measureable differences can be recorded in the child's behavior. Also the degree to which the children accept responsibility for a behavior and carry on the activity by themselves can be used as a measure of the success of parent involvement. For example, it can be observed whether the child puts on his/her own hearing aid, turns it on and indicates to someone who can help when it doesn't work.

The Community Interaction Early Education Program (CIEEP) Program at Tulsa University, involves the child and family in activities in the center, the home and the community. The community component often includes an additional education program. Information has been collected on child-change data, specifically pre and posttest scores on the Bayley and the McCarthy, throughout the program. At present, the project is attempting to ascertain the impact of parent involvement on child-change. Variables being studied are parent/child attendance for center sessions and home sessions, amount of time spent by parents on home program activities, and parent attendance at extra sessions for which they had indicated a need, for example, behavior management training sessions. This data will be analyzed in late spring, 1982 to determine if correlations exist between child-change and these specific types of parent involvement.

Although child-change data is a sought-after result of intervention, caution must be observed when using child-change data to evaluate parent behavior for two reasons:

1. There is little evidence that one can make valid inferences that a given increment of child change is due to an increment of parent training.
2. The number of variables acting on the child and on the parent-child interaction are many, of which those affected by the parent education program are only a small fraction.

## Summary

In this paper we have tried to discuss some of the types of involvement that might be offered, stressing that they must be individualized and that there is a distinction between being involved with the child and being directly involved with the child's school program.

In a study of parent involvement as viewed by parents, it was reported that informal contact with their child's teacher was the preferred involvement of most parents (Winton & Turnbull, 1981). Parents felt that the two major characteristics of these contacts were that they be frequent, and that information be shared in a give-and-take fashion.

A good parent involvement program will provide opportunities for allowing the parents to meet their individual needs, recognizing that these will vary from individual to individual and within an individual over time. Successful parent involvement programs should be predicated on the premise that parents do have valuable contributions to make to the growth of their child, that programs must provide for individual differences, and the recognition that each parent is capable of growth.

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